

# SPINAL COURIER

The spinal cord disability information source for Arkansans since 1989

Vol. 18 No. 3

April 2007

www.spinalcord.ar.gov

# 2007 Conference "Achieving Your Dreams"

Mark your calendar for the biggest, best ASCC conference yet! Achieving Your Dreams will be held on Friday, **June 15**<sup>th</sup> at the Arkansas 4-H Center in west Little Rock. The program is already full of great speakers, exhibitors, demonstrations and prizes. Everyone will find a chance to learn something new. Continuing Education Units are available for healthcare professionals; scholarships and travel stipends are available for ASCC clients and their families.

This year's conference will feature Glenn McIntyre, cofounder of Mc-Intyre & Associates, accompanied by his service dog, Boylan. With humor and riveting insight, Glenn speaks straight from the heart. His authority and wisdom are born from his hardwon personal experience and acclaimed professional



Glenn McIntyre and his service dog Boylan.

expertise. As a young police officer, Glenn McIntyre's life was altered forever when his vehicle was hit by an impaired driver. The crash left him with paraplegia, breaking his back in 17 places. Glenn had to learn to endure, overcome and then excel at life again. And he did! Not only did Glenn return to law

enforcement for another 14 years, he also became a much sought after professional speaker, an instructor at California State University Northridge and a top-ten nationally ranked wheelchair tennis competitor. Perhaps more importantly, Glenn developed the skills for success that he has shared with audiences since 1989.

By overcoming challenges and through his commitment to inspiring and educating others, Glenn is living proof that you can, achieve your dreams! Glenn's presentation is sponsored by Baptist Health Rehabilitation Institute.

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## **Christopher Reeve Paralysis Foundation Donation**

The Christopher Reeve Foundation announced in January that the Arkansas Spinal Cord Foundation (ASCF) was the recipient of an \$8,000 Quality of Life grant. The grant was one of 90 totaling \$717,404 awarded this year.

"The Christopher Reeve Foundation is proud to carry out Christopher and Dana Reeve's amazing legacy and make a real difference in the lives of people living with paralysis, their families and communities" said Kathy Lewis, CRF president and CEO, upon making the announcement.

The funds will help establish Coming Home, a new project of the Foundation, working with the Arkansas Spinal Cord Commission to assist newly injured individuals in obtaining needed home modifications and ramping.

"We look forward to utilizing this grant to help us recruit more organizations to contribute to this exciting project," said ASCF Board Chair Sandy Turner. "Our foundation looks forward to supporting the work of the Commission to meet the needs of Arkansans with spinal cord disabilities."

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#### SPINAL COURIER

Published quarterly by Arkansas Spinal Cord Commission

Cheryl L. Vines Executive Director

Thomas L. Farley Editor

Commission Members:
Joe McNiel, Chair
Jimmy Ashley
James Miller
Sandra Turner
John Wyrick

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or e-mail us at:

courier@arspinalcord.org

# With Thanks

Donations this quarter from:

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In Memory of Edward Gibbs
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In Memory of Maria Sullivan
Sherry Woolridge

### SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

### **Fall Hunting Groups Now Forming**

Dear Readers:

Hunting parties for the 2007 season for persons with a disability are now organizing. Get your name in early to be included in one of these fun filled getaways. Several hunts, open to both men and women will be scheduled. Call me for anticipated hunt dates.

In addition, we are organizing a hunt for only women with disabilities.

This hunt, limited to five women, will be held at Cooks Lake near Cascoe, AR. Sponsored by AGFC and USFWS, the agencies hope to make this unique hunt an annual event.

Don't delay! Call me at **479-890-5751** if you have questions or to sign up for one of these hunts.

Toney LeQuieu ASCC Russellville Case Manager

## From the Director

Did you ever think of the word *support*? It has lots of meanings. According to the dictionary those meanings include, ". . . to endure bravely, promote an interest, defend rights, vote for, hold up, serve as foundation, provide subsistence . . ." Like I said it has a lot of meanings. My favorite was the last entry, "to keep something going." That is how I think of support. During my own time of loss last year, I had a lot of support from friends, family, colleagues, neighbors, even people I'd never met. They kept me going.

Sometimes we need support just for our day-to-day lives, something to keep us going. We find it in many ways. One way is through support groups where people with common interest or experience help each other keep going. The Commission has five active support groups and is looking to start three more in 2007. Support groups aren't just for those who are weak or needy or grieving; sometimes, they are just to keep you going! Think about joining one of our groups this year.

Enjoy the beautiful colors of spring! I look forward to seeing you at our conference in June.

Cheryl L. Vines

ASCC accepts tax-deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788** / **1-800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

AR Spinal Cord Commission 1501 N. University, Suite 470 Little Rock, AR 72207

### New Faces in the Little Rock Office

The past few months have brought several changes to the Little Rock office. Two new staff members have arrived to provide much needed support to the Case Management office.

Teresa Sherman began her duties in February as an ASCC Case Management secretary. She will be providing support to Case Manager Dee Welsh and Intake Coordinator John Breen. Teresa's experience in providing office support to multiple staff will assist her well in the Case Management office. "I am very impressed by the way Teresa has stepped in and learned the procedures so quickly," stated Client Services Administrator Patti Rogers.

Teresa is a native Arkansan originally from McNeil. She, husband Don, daughter Sarah, 16, and son Matthew, 14, live in Benton. Raising two teenage children doesn't leave a lot of free time but Teresa loves to cook and has a vast cookbook collection. She also loves the outdoors and tries to hunt and fish as often as she can. "I was an only child so when my Dad went hunt-

ing and fishing I always went along and learned to love it," Teresa reflected.

Dee Welsh joined the Little Rock Case Management office in January. Dee has been an ASCC employee for the past 14 years quietly spending her time in our Research and Statistics department as a Administrative Assistant. Many of you will recognize Dee as she was the coeditor of the Spinal Courier for many years. So, Dee is not exactly new to the agency but rather has changed positions. It has been a very well kept secret that Dee actually has a bachelor's degree in Social Work from the University of Arkansas at Fayetteville. "We are pleased that Dee can now utilize her Social Work degree more effectively and provide much needed assistance to the individuals in Lonoke, White and part of Pulaski

In addition to her full-time position as ASCC Case Manager Dee is also employed part-time at the Arkansas

County," stated Ms. Rogers.



Teresa Sherman (left) and Dee Welsh.

Arts Center. Dee enjoys attending horse shows, watching movies especially fantasy/sci-fi, listening to music and reading. She lives in west Little Rock with her Siamese cat. Her daughters are currently living abroad: Maren, 24, is teaching English in Japan and Jayce, 22, is touring Europe.

The Commission members and staff of ASCC feel fortunate to have such qualified individuals working with our agency. Welcome aboard, Teresa and congratulations on your promotion Dee!

### Conference

Continued from page 1

Following Glenn, Marilyn Hamilton, Vice President of Global Strategic Planning for Sunrise Medical and one of the inventors of the quickie wheelchair, will bring a strong consumer message as she discusses the future of choice in durable medical equipment, including the latest Medicare regulations on wheelchair purchases.

National Spinal Cord Injury Association Executive Director Marcie Roth will discuss, Lessons Learned: Disaster Preparedness for People with Disabilities. This topic should concern everyone especially in the aftermath of Hurricane Katrina and other natural and

man-made disasters. Learn what you need to do to "Be Prepared."

Other topics include: updates on bowel and bladder management, returning to work without losing your benefits, identifying and treating depression, outdoor recreation adaptations and many others.

In addition, the conference always provides an opportunity to see the latest technology, supplies and wheelchairs, visit with old friends and meet new ones! Set aside time now to attend this educational event.

A brochure and registration form will be mailed to all clients in early May or phone **1-501-296-1788** for a registration form.

### New Health Guide for Parents of Children Living with Spina Bifida

The Spina Bifida Association of America has published a guide for parents covering spina bifida issues and information from newborn to teenager. Topics include: what to expect, neurological function and progress, urologic and bowel function and progress, orthopedic function and progress, general health promotion, mental health, social development and learning.

SBAA members may purchase the guide for \$19.30 (non-members \$22.30). Call the National Resource Center at **800-621-3141 x35** to place an order or download an order form from SBAA's web site at www.sbaa.org.

SPINAL COURIER — 3

# Managing Bladder Infections in Spinal Cord Injury

By Tom Kiser, M.D., ASCC Medical Director

The problem with diagnosing bladder infections in persons with spinal cord injury is that patient complaints may indicate a bladder infection or some other problem; and the other problem may not require antibiotics.

For example, the following are bladder symptoms that may or may not indicate a bladder infection:

"My urine smells bad." This can be due to an alkaline (pH>7.0) commonly seen if too many carbonated beverages are consumed.

"My urine is cloudy/dark." This can be due to decreased fluid intake, sediment in the bladder.

"I have a fever." Multiple things can cause a fever ranging from a heat stroke to infection.

"I have increased fatigue." Again, the problems can range from anemia to sleep apnea.

When I see patients in clinic I usually ask

them how many bladder infections they have had since I last saw them. The answer is usually that they were treated with antibiotics once or twice for a bladder infection. When I asked them what were the signs of the bladder infection, the answers are usually pretty vague—"My urine was dark," or "It smelled worse than normal," or "It was cloudy." When I ask about symptoms they usually report that they either had none, or they had a slight fever. Often they received antibiotics without a urinalysis or culture being conducted, and if they did send off a urine sample they tell me, "The doctor said I had bacteria in my urine." When I ask if they said anything about

white blood cells in the urine, which would indicate the bladder's response to an infection, the answer is usually "No."

When I am faced with a question about a possible bladder infection, I want to know how the bladder is being managed. The method of bladder management is very important in reducing the risk of bacteria and the incidence of a urinary tract infection (UTI). In one medical study<sup>1</sup> it was reported that in patients using an indwelling catheter, the incidence of UTI was 2.72/100 person days, while in patients using intermittent catheters, the incidence was 0.41/100 person days, and in patients using a condom catheter, it was 0.36 episodes/100 person days. In other words, a person with an indwelling catheter was 7 times more likely to get a UTI than someone using intermittent catheterization.

The bottom is line is that, if you are having frequent, recurrent bladder infections, a workup is required.

However, when either indwelling or intermittent catheterization is required long term, bacteria in the urine eventually occurs in almost all patients. Routine use of antibiotics can lead to the development of antibiotic resistant organisms which then requires more potent and expensive antibiotics. Antibiotics are only recommended for a symptomatic (meaning fever/ chills/illness) bladder infection with proven pyuria (> 10 white blood cells per high power field on urinalysis) and not asymptomatic bacteria in the urine.

Some of you may say, "I have gone a long time without a bladder infection and I have used an indwelling



ASCC Medical Director Tom Kiser, M.D.

catheter for years." (Please knock on some wood, nearby.) Some of this can be explained by the fact that not all bacteria are the same, and some are more likely to cause problems than others. A novel experiment by Hull et al.<sup>2</sup> looked at instilling a special bacteria, E. Coli 83972, into the bladder, which was known to cause asymptomatic bacteria (i.e., good bacteria) and bladder colonization. In those subjects who were effectively colonized with E. Coli 83792 the infection rate dropped from 3.1 UTIs/year to 0 UTIs /year. The problem they faced in the study was maintaining colonization (it was only achieved

in 13 of the 21 subjects), and the use of antibiotics caused a loss of colonization and a return of UTIs. This would suggest that if you are having good success with very few bladder

infections you may be colonized with a good bacteria and you should try to avoid antibiotics if you possibly can without compromising your health.

What about prophylactic use of antibiotics? Some of you take antibiotics daily to decrease the amount of UTIs you have. This has been successful for some of you, but this is controversial. In a metaanalysis of 15 trials that looked at the use of antibiotics, the use of prophylactic antibiotics increased the presence of antibiotic resistant bacteria two fold. In general, if prophylactic antibiotics, such as Bactrim DS or Macrobid, are the only thing that Continued on page 5 - see "Bladder Infections"

## Time to Sign Up for Camp!

It's hard to believe—but Spina Bifida Camp is just around the corner! Each year, the Arkansas Spinal Cord Commission, in cooperation with Med Camps of Arkansas and Camp Aldersgate, sponsors a weeklong camp for children ages 6 to 16 at Camp Aldersgate. This year's camp is **June 24** through **June 29**, **2007**.

There is no fee for this week of camp. However, each family is responsible for providing transportation for their child to and from Camp Aldersgate.

Camp Aldersgate is located in a quiet, rustic area in west Little Rock near Baptist Health Medical Center. And, as stated in the Camp's brochure:

The Med Camps program provides weeklong residential camping sessions for children with specific medical and/or physical challenges. This also includes

staff who are one-on-one—nurses administer medications and provide health care on a 24-hour basis. Camp physicians visit the camp and are on call throughout the week. The camping program is designed to increase campers' self-esteem by creating opportunities to meet personal challenges. Participation in personal hygiene and housekeeping chores encourage campers' responsibility and independence. They learn to work in harmony with others, broaden skills and interests, as well as develop initiative and resourcefulness.

Camp offers most traditional summer camp activities such as campfires and music, canoeing, fishing, arts and crafts, swimming and nature hikes. Activities that focus on creating more of a personal challenge include an accessible adventure/challenge ropes course, hand and/or foot driven catamarans, adapted

archery, and a big hit with older campers, SCUBA diving.

All cabins, the health care center and the multi-use activity center are air-conditioned and fully accessible. In addition, from the time camp starts on Sunday afternoon until camp ends on Friday morning, trained counselors, volunteers and Med Camps medical specialists supervise the campers.

This is a time of growth and learning for the campers while having fun. Applications and brochures were sent out in March.

We have room for 45 campers, and acceptance is based on a first-come, first-served basis so mail your application in today! If you have questions regarding Camp, or if you did not receive your application, you can call Mary Jo Stanton at 501-296-1788 or 800-459-1517 or email mjstanton@arspinal-cord.org.

See you at Camp!

### **Bladder Infections**

Continued from page 1

has worked for you, I prefer to limit their use to only when you have symptoms of a bladder infection and then for a limited time. This can be done empirically (without a urinalysis) but it is also fraught with problems, because patients are frequently wrong in predicting when they have a UTI based on symptoms. In a study by Linsenmeyer and Oakley<sup>3</sup> 39 percent (57/147) of subjects were in error when they thought they had a UTI.

The bottom is line is that, if you are having problems with frequent, recurrent bladder infections, a workup is required. The suspected bladder infection may not be a UTI but some other problem. However, if it is a UTI it should be treated appropriately with the correct antibiotic. The workup requires a urine culture to determine the

most appropriate antibiotic. Then your method of bladder management needs to be scrutinized and adjusted to minimize bladder infections. This workup can range from: a cystoscopy to rule out bladder stones; to urodynamics to determine bladder pressures and post void residual volumes; to the avoidance of antibacterial soap to avoid developing antibiotic resistant bacteria; and finally to a discussion of either a new bladder management technique or possible surgical options.

#### References:

1 Leoni ME, De Ruz AE. Management of urinary tract infection in patients with spinal cord injuries. Clin Microbiol Infect 2003;9:780-785.

2 Hull R, Rudy D, Donovan W, Svanborg C, Wieser I, Stewart C, Daroiche R. Urinary tract infection prophylaxis using Escherichia Coli 83792 in spinal cord injured patients. J Urol 2000;163:872-877.

3 Linsenmeyer TA, Oakley, A. Accuracy of individuals with spinal cord injury at predicting urinary tract infections based on their symptoms. J Spinal Cord Med 2003;26(4):352-357.

# Participants Wanted for Spina Bifida Focus Group

Partners for Inclusive Communities at UAMS would like to invite you to a meeting in North Little Rock on Saturday, **April 28th** from 10 a.m.-12 noon. We will be talking about problems and solutions to help youth with spina bifida transition to adulthood.

Participation is limited to 10 adults with spina bifida and 10 parents of adults with spina bifida. You will receive a \$25 gift certificate for your time and your mileage costs will be reimbursed.

Your input will help us develop a plan for Arkansas to assist youth with spina bifida as they transition to adulthood.

Thank you!

Call Mary Jo at: **501-682-9900** or **1-800-342-2923** to sign up.

SPINAL COURIER — 5

# Up Close and Personal: Toney LeQuieu

This is the latest in a series of articles profiling the ASCC Case Managers.



Toney LeQuieu joined the ASCC staff as a Case Manager assigned to the Russellville office in September 2006. Toney provides services to clients in Yell, Perry, Conway, Pope, Van Buren, Newton and Boone counties. Reflecting on his role, Toney stated, "I am constantly amazed at the abilities of an individual with a disability."

Toney has a Therapeutic Recreation degree and is a Certified Therapeutic Recreation Specialist. Before coming to ASCC, Toney worked for nine years as a Recreation Therapist at Health South Rehabilitation Hospital in Jonesboro. His experience in wheelchair and home evaluations and conducting patient education groups has been a great asset. "We were fortunate to find someone with Toney's experience in working with individuals with spinal cord disabilities. He is doing an excellent job." commented Client Services Administrator Patti Rogers.

In his free time Toney is a volunteer event coordinator also with the Arkansas Disabled Sportsman Association and coaches age 10 and under girls' softball.

Toney, his wife Elizabeth and daughter Ashley live in Pottsville, a small community just outside Russellville. His wife works as an Occupational Therapy Instructor at University of Central Arkansas.

### **PROFILE:**

*Date And Place Of Birth:* February 26, 1971, in Little Rock, Arkansas.

**Family Members:** My wife Elizabeth, my nine year old daughter Ashley, along with Abbie, a black labador retriever and Rufus, a Toy Fox Terrier.

If I Did Not Live In Arkansas, I Would Want To Be: In Montana or Alaska.

I Absolutely Will Not Eat: Snails.

One Thing People Would Find Surprising About Me Is: My sense of humor.

My Favorite Movie Is: Eight Seconds.

My Favorite Song Is: Stairway to Heaven.

*The Last Book I Read Was:* Chasing the Dime by Michael Connelly.

*I Am Most Comfortable With People Who:* Have similar interests as myself.

My Favorite Pastimes Are: Being outdoors and sports.

*The Best Advice I Ever Received Was:* "Don't sweat the small stuff and everything is small stuff."

My Favorite Saying Is: "If it ain't broken, don't fix it."

*I Knew I Was Grown Up When:* I realized how much toothpaste cost.

The One Thing I Always Wanted To Do But Have Never Had The Chance Was: Learn to fly an airplane.

One Word To Sum Me Up: Tenacious.

### Annual Corvette Car Show Aids SBAAR

The Corvette Club of Central Arkansas will hold their annual spring Corvette Car Show benefiting the Spina Bifida Association of Arkansas (SBAAR) on April 20-22, 2007. According to SBAAR President Jim Rucker, "The Corvette Car Show is the primary source of support for the association's yearly events, such as the Christmas party and Fall Festival."

The Corvette Car Show will be held at the Old Train Station in Hot Springs. Hundreds of Corvettes from all over the Midwest and South are expected to be on display. Admission is free. Volunteers will be needed to make this event a success. Please call Vicki at 501-978-7222 for more information and to volunteer. In addition, the national spina bifida conference will be held in Louisville, KY on June 24-27, 2007. You can register online at www.sbaa.org.

# 2007 Arts Festival: Bringing Out The Best in Me!

The 8<sup>th</sup> annual festival of the arts for individuals with disabilities will be held Friday, **May 4, 2007**, 10:00 a.m. – 1:00 p.m. at Clear Channel Metroplex, 10800 Colonel Glenn Road in Little Rock.

The festival celebrates therapeutic recreation and features hands-on crafts, art, music, entertainment and refreshments. Activities this year include sand art, clay pots, beading, face painting, snag golf, a climbing wall and more. The facility is very accessible and admission is free!

The Arts Festival is sponsored by the Therapeutic Recreation program of Little Rock Parks and Recreation Department.

For additional information contact Cindy Covey at **501-244-5489** or **CCovey@littlerock.org**.

# Emergency Preparedness for Persons with a Disability

Have you considered what **you** would do in the event of a malicious act of terror, a house or apartment fire or a medical emergency? Disasters of all kinds affect everyone, therefore, making a plan about what **you** will do so in an emergency situation makes sense.

Take responsibility to prepare for emergencies that may affect you. We all know our own strengths and weaknesses, skills and abilities. You need to become actively involved when an emergency occurs. By taking responsibility, you can create a workable plan to meet your unique set of circumstances when an emergency occurs.

To create an effective plan consider questions such as these:

What type of assistance will I need in case of an emergency evacuation?

What is the best way for me to be evacuated without hurting myself or others?

What arrangements do I need to make for my service animal if I am hospitalized?

What are the three most important items I must take with me during an emergency evacuation from my work or living environment?

By taking the responsibility to ask and answer questions such as these, you eliminate fear and gain control when an emergency arises.

In emergencies, people need to know what to do without thinking about it. We need to act quickly and effectively and that takes practice.

Practicing your plan about every two months is a good way to make sure that when emergencies occur you will respond automatically without confusion and fear. Practice makes perfect. An emergency kit is essential. Here are some suggestions in helping you to assemble a personal emergency kit. Remember, you may be away from home for more than a few hours. Gather items such as:

Batteries, flashlights, candles and matches.

A battery operated radio (with NOAA Alert Channel capabilities).

A set of comfortable clothing if an overnight stay becomes necessary.

Non-perishable food and an adequate supply of water. This should be replaced every six months.

A blanket and a blow-up pillow.

An emergency supply of your medications.

A basic first aid kit.

Basic needs for your disability.

A battery charger for your wheelchair.

Pictures of your loved ones.

Important documents such as birth certificates, marriage certificates, etc.

Add things that are unique to your own specific needs.

Place the gathered items in an easy to carry duffel bag or backpack. Store your kit in a closet closest to your escape route.

List your medical history briefly on a piece of paper. Include medications and dosages, allergies, insurance coverage and contact information of your physician, family and friends. Place this information in your kit in a waterproof bag. Also place a copy of it in your home where caretakers know to find it.

Be prepared! Disasters, emergencies and acts of terror are all a part of life these days. It's what you do before an emergency that makes the difference!

SPINAL COURIER — 7



# The Squeaky Wheel

The squeaky wheel . . . gets the grease! This column is about grease—things that make life for persons with spinal cord disability go smoother and ease your way in the world. "Things" can be hints, equipment adaptations, innovations, tricks-of-the-trade, procedural shortcuts, life experiences, or things you "should have done but didn't."

Pat Cole of Harrison, AR suggested that we all learn from her mistakes. Here is her lesson number two:

While I was in the hospital recovering from surgery to amputate two of my toes, I needed to use the toilet. Because I was sent to the hospital so quickly I didn't have the opportunity to take my elevated toilet seat with me. So. I asked to use one of those seats that rolled over the toilet. Since I was uneasy transferring onto it alone, I asked my aide to assist me. Instead of sitting me down gently, she plopped me down hard. I don't have sensation on my bottom, so I had no idea if any damage was done.

When I got home and inspected my body, I found a huge bruise with a large swollen area in the middle. I was smart enough to stay off of it but eventually it started to seep. I went to my doctor and he said I

would have to have it surgically debrided, which I did.

That was well over a year ago and I am still lying in bed 22 hours out of the day trying to get it to heal.

If you have to spend time in a hospital for any length of time, by all means, try to take your own equipment with you.

We invite you to send in your helpful hint—your bit of "grease." Contact your ASCC Case Manager, write us at Spinal Courier, Arkansas Spinal Cord Commission, 1501 N. University, Suite 400, Little Rock, AR 72207 or e-mail us at **courier@arspinalcord.org** and put "Squeaky Wheel" in the subject line.

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